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TITLE: **Impact of Institutional - and Individual – Level Discrimination on Medical Care & Quality of Life among Breast Cancer Survivors**

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14. ABSTRACT
During this reporting period, we successfully conducted 31 qualitative one-on-one and focus group interviews with breast cancer survivors from 7 racial/ethnic groups, undertook rigorous qualitative data analysis and have begun to identify several novel emerging themes. We have also begun to develop the quantitative survey for cognitive testing and have conducted a comprehensive review of existing tools for the constructs of interest. We expect to report the qualitative findings in 2 manuscripts and have plans for a third manuscript based on the instrument development process.

15. SUBJECT TERMS
Qualitative analysis, focus group, cognitive interview, instrument development

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INTRODUCTION

The objective of this study is to measure the prevalence and impacts of discrimination at the institutional- and individual- level to identify the underlying factors contributing to disparities in breast cancer diagnosis, treatment, and quality of life. The specific aims are to: 1) develop a survey tool tailored towards cancer patients for assessing discrimination in health care settings; 2) quantify the prevalence of individual- and contextual-level discrimination across racial/ethnic groups; and 3) assess the effects of individual- and contextual-level discrimination on disparities in: a) late stage diagnosis, b) cancer treatment (including BCS and adjuvant radiation), and c) QOL. This study comprises two components: developmental (Aim 1) and application (Aims 2-3). The developmental component uses qualitative research to develop an instrument tailored for breast cancer patients. Because tools have not been developed for cancer patients nor for different races/ethnicities, we will conduct focus groups and qualitative (one-on-one) interviews to discern relevant discrimination topics. The topics, together with existing instruments, will be used to develop an instrument to be cognitive-tested in a small sample of patients. We will then conduct a pilot test, including a reliability test-retest, of the instrument and field methodology to optimize its reliability. In the application component, we will conduct a cross-sectional epidemiologic study using a multilevel approach by incorporating individual- and neighborhood-level information including: 1) previously collected geographic information systems (GIS) data about the social and built environment; and 2) telephone interviews (~14 months after diagnosis) with a population-based cohort of breast cancer patients.

BODY

The Statement of Work for the first two years of the study is as follows:

Task 1 Obtain IRB approvals, design and obtain approvals on focus group and qualitative interview instruments, translate and back-translate instruments, develop study tracking system and training materials, Months 1-6

a. Prepare and submit IRB applications for DOD and NCCC.
b. Apply for cancer registry data from the Greater Bay Area Cancer Registry (GBACR).
c. Develop MS Access tracking system.
d. Develop interviewer training manual.
e. Translate, back-translate, convene meeting(s) to decenter instruments.
f. Hire staff.
g. Obtain first case listing data from the GBACR, download into tracking system.
g. Organize community advisory committee meeting to introduce study and obtain feedback about general research strategy.

Deliverables: IRB approvals, finalized instruments for focus group and qualitative interviews, community advisory committee feedback

Task 2 Conduct focus group and qualitative interviews, Months 7-12

a. Select breast cancer patients for contacting regarding focus group and qualitative interviews.
b. Recruit breast cancer patients for fulfilling the numbers of required focus group and qualitative participants for each racial/ethnic group.
c. Conduct focus group and qualitative interviews.
d. Transcribe interviews.

Deliverables: completed focus group and qualitative interviews, transcripts of completed interviews

Task 3 Conduct qualitative data analysis, design epidemiologic survey instrument, Months 13-18

a. Code the transcribed interviews.
b. Conduct thematic-driven qualitative data analysis.
c. Design epidemiologic survey instrument.
d. Translate epidemiologic survey instrument.
e. Develop and obtain IRB approval for recruitment materials and procedures for cognitive interviews.

Deliverables: completed qualitative data analysis, epidemiologic survey instrument and recruitment materials for cognitive interviews

Task 4 Conduct cognitive interviews, revise epidemiologic survey instrument as necessary, Months 19-21

a. Select breast cancer patients for contacting regarding cognitive interviews.
b. Recruit breast cancer patients for fulfilling the numbers of required cognitive interviews for each racial/ethnic group.
c. Conduct cognitive interviews.
d. Convene study staff meetings to discuss results from cognitive interviews and to revise instrument as necessary.

Deliverables: completed cognitive interviews, refined epidemiologic survey instrument based on cognitive testing

Task 5 Conduct pilot testing, revise epidemiologic survey instrument as necessary, Months 22-24

a. Select breast cancer patients for contacting regarding pilot test interviews.
b. Recruit breast cancer patients for fulfilling the numbers of required pilot test interviews for each racial/ethnic group.
c. Conduct pilot test interviews.
d. Conduct reliability test-retest interview.
e. Conduct data analysis.
f. Convene study staff meeting to discuss results from pilot test interviews and to revise instrument as necessary.
g. Convene community advisory committee to review study instrument and field recruitment methods and obtain advice regarding appropriateness, relevance, and feasibility.

Deliverables: completed pilot test interviews, refined epidemiologic survey instrument and field methods based on pilot testing, community advisory committee feedback

Task 6 Conduct epidemiologic interviews, GIS analysis to create neighborhood variables, Months 25-40

a. Select breast cancer patients for contacting regarding epidemiologic interviews.
b. Recruit breast cancer patients for the epidemiologic interviews.
c. Conduct epidemiologic interviews.
d. Design data entry system in MS Access.
e. Edit questionnaire, conduct double data entry.
f. Conduct quarterly, interim data analysis to look for unusual data patterns.
g. Clean and prepare epidemiologic interview data for analysis.
h. Conduct GIS analysis to create study-specific neighborhood measures and merge to interview dataset.
i. Create statistical program to conduct multilevel modeling analysis.
j. Conduct test-runs of multilevel modeling analysis.

Deliverables: completed epidemiologic interviews, epidemiologic analytic dataset, multilevel modeling analysis program

Progress

Since the last annual report, we have completed most of the tasks outlined in the Statement of Work. We have had some set-backs in the study progress due to staffing issues, maternity leave, and the qualitative phase taking longer than expected in general. We did successfully conduct a total of 24 one-on-one qualitative interviews with women from 7 racial/ethnic groups, plus 3 women from an “other group” (comprising various other smaller racial/ethnic groups), and 7 focus-groups (Appendix A). As we made the decision to be more rigorous about our qualitative analysis process so as to benefit from the richness of the depth of the information, the transcription, translations, and data analysis have been time consuming. Five coders have completed coding these 31 interviews and we expect to complete the thematic analysis by early Spring 2010. We plan to summarize the qualitative results into 2 manuscripts that we expect will be submitted for publication in the late summer of 2010.

At the same time, we have begun the process of designing the epidemiologic instrument for cognitive testing. We have undertook a rigorous process of comprehensively reviewing existing survey questions for all of our major constructs of interest. The survey design team and the qualitative analysis team have begun meeting together to adapt existing survey questions, and design new questions where existing questions do not exist to capture an emerging theme of interest. In doing this work, we have realized that there is very little existing tools that capture the qualitative themes that we have found. As we will be rigorously testing the tools that we will be developing, we will also be documenting the process and reporting our results in a separate process manuscript. We believe that these research questions that are currently being developed will have broad applicability to a number of different disease outcomes.

At this time, we have a draft of the epidemiologic instrument, which we have sent to our scientific advisors for feedback. Beginning in January, we will begin designing our cognitive instruments (cognitive response form, cover letters, phone scripts, informed consents, etc), solicit feedback from the Community Advisory Committee, conduct the translations and back-translations, and submit all of the materials for IRB review in April. We expect to receive IRB approvals in May, make modifications to the instruments and forms as needed, and conduct the cognitive interviews in June-August 2010. To make up for the study delays, we plan to increase our interviewers' levels of effort during the epidemiologic phase and we expect that we will be able to complete the epidemiologic interviews in a considerably shorter amount of time than originally designed. In addition, we have already begun to assemble the institutional and contextual data, which are tasks outlined in Task 6 of the Statement of Work.

KEY RESEARCH ACCOMPLISHMENTS

- Successfully conducted 31 qualitative one-on-one and focus group interviews with breast cancer survivors from 7 racial/ethnic groups.
- Undertook rigorous qualitative data analysis and have begun to identify several novel themes.
- Conducted comprehensive review of existing tools for constructs of interest.
- Begun to develop novel survey questions based on qualitative themes.
- Process has lead to potential for at least 3 novel manuscripts.

REPORTABLE OUTCOMES

- In December 2009, we submitted a grant application to the ASCO/Komen Improving Cancer Care grant to extend the study to include medical records abstraction. If funded, this additional funding would provide the opportunity to collect more detailed treatment and comorbidity data from clinical records, beyond what would be available from patient self-report and the cancer registry.

CONCLUSIONS

Despite delays, we have made good progress and overall, the study has been largely successful thus far, with many important themes emerging from the qualitative data analysis.

REFERENCES

None.

APPENDICES

Appendix A:

Study focus group and qualitative interview outcomes and response rates by race/ethnicity and interview type

Interview type / Outcome	Numbers of subjects by race/ethnicity							TOTAL
	White	**Chinese**	**African American**	**Hispanic**	**Filipina**	**Japanese**	**Other**	
	Focus group							
Invitation letter sent	50	87	46	52	61	33	n/a	329
Ineligible	7	2	1	14	16	7	n/a	47
Refused	15	29	3	14	31	11	n/a	103
Participated	6	11*	6	5	3	5	n/a	36
Lost to follow up	5	-	-	10	9	1	n/a	25
Not needed**	12	23	7	7	-	8	n/a	57
Not reached***	5	22	29	2	2	1	n/a	61
Response rate, % (of contacted and eligible)	28.6%	27.5%	66.7%	26.3%	8.8%	31.3%	n/a	25.9%
	Qualitative (one-on-one) interview							
Invitation letter sent	20	45	18	18	20	19	21	161
Ineligible	2	4	-	5	1	1	7	20
Refused	4	19	1	6	5	11	4	50
Participated	3	6****	3	3	3	3	5+	26
Lost to follow up	1	3	-	1	-	1	1	7
Not needed	10	6	6	3	2	2	-	29
Not reached	-	7	8	-	9	1	4	29
Response rate, % (of contacted and eligible)	42.9%	24.0%	75.0%	33.3%	37.5%	21.4%	55.6%	34.2%

* 2 focus groups; 6 participants in Mandarin focus group and 5 participants in Cantonese focus group.

** Not needed = participants who were contacted but not needed for the focus group or qualitative interview because the goal for number of participants was reached; these women will be re-contacted for subsequent phases of the study.

*** Not reached = participants who had not been reached by the time we reached our goal numbers for the focus group or qualitative interviews, but who are not necessarily lost to follow up or whose addresses still need to be traced.

**** 3 Mandarin; 3 Cantonese

+ 2 Discovered ineligible after interviewing.